

PUBLIC HEALTH COMMITTEE TESTIMONY – HB 6200

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Our family's nightmare with Lyme Disease began almost three years, when our 13 year-old daughter suddenly became disabled with extreme vertigo and chronic fatigue. Her initial blood test for Lyme was negative, largely because our pediatrician only administered the Elissa blood test instead of the more reliable Western Blot test. When she finally got a positive Lyme test from an infectious disease specialist six weeks later, the damage had been done. She had already missed the last two months of her seventh grade year due to chronic fatigue, inability to concentrate, insomnia, and vertigo. Following the IDSA guidelines, the infectious disease specialist put her on a three-week course of amoxicillin, telling us that she would be fine. But he was wrong. She relapsed with a high fever, chronic fatigue and dizziness. We went back to our pediatrician, who put her on doxycycline and amoxicillin for 30 days followed by an additional 20 days of amoxicillin. After returning to her eighth grade classes in Sept., she relapsed two days later with the same debilitating Lyme symptoms. Our pediatrician then told us that he was out of treatment options. Although he himself had been treated with long-term antibiotics for Lyme disease, he said his pediatric practice didn't advocate this type of protocol. This was our first introduction into the politically charged and hypocritical world of Lyme disease. Finally we saw a pediatric Lyme specialist, who after a thorough two-and-half hour clinical evaluation and consultation, put our daughter on a six-month course of antibiotics. Fast forward to two and half years. The odyssey has been long and painful filled with suffering and despair for our entire family. The long-term antibiotics were not a quick fix, but gradually our child, a former star athlete and conscientious student, began to get her life back together. She returned to school full time in February of her eighth grade year. She was still plagued with chronic fatigue, but the long-term antibiotics improved her concentration and energy level to the point where she could do her schoolwork. Over time, with the help of two Lyme disease specialists, she finally went off the antibiotics this past December. She is now on herbal remedies indefinitely and we are hopeful that they will keep her Lyme disease at bay. Thankfully, our 15 year-old daughter has resumed the life of a normal teenager: she swims competitively on the high school team, takes challenging academic classes, and has an active social life. The real tragedy is that there are hundreds of thousands of patients who aren't so lucky. They are being denied successful long-term antibiotic treatment, either because their doctors are Lyme-illiterate or afraid to prescribe them for fear of harassment. I urge you to please do the right thing and pass this important piece of legislation. We need to protect and liberate our physicians, so that they can once and for all clinically diagnose and successfully treat Lyme disease by prescribing long-term antibiotics without fear of reprisal. Thank you.

Eileen Rice